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The present study is a prospective examination of the impact of genetic testing for breast-ovarian cancer susceptibility on marital relationships and the quality of life of husbands. Participants are women (age 18 and older) who are members of families in which a disease conferring mutation has been identified and their spouses. Interviews of husbands and wives are completely by telephone prior to receiving test results, as well as 1-, 6-, and 12-months after test disclosure. The preliminary data showed that wives (n=49) were more likely to use avoidance, have intrusive thoughts, and experience psychological distress compared to husbands (n=35). Wives also rated higher marital satisfaction. The husbands scored lower at baseline on four of the measures of interest (the presence of intrusive thoughts, general psychological distress, state anxiety, and marital adjustment) than 1-month after follow-up (n=6). The results of the preliminary analysis suggest that husbands may experience less psychological distress than wives at the baseline assessment (pre-mutation disclosure). However, the level of distress may increase for the husbands within one month of learning of the wife's mutation status. Further analysis when more disclosures have been completed will elucidate the association between mutation status outcome and these psychological measures.

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Sharon Mayo
Principal Investigator's Signature

May 30, 2000
Date

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## INTRODUCTION

The *Impact of BRCA1/2 Testing on Marital Relationships* is a prospective longitudinal study designed to examine the impact of genetic testing for breast-ovarian cancer susceptibility on the marital relationships of women at risk as well as the impact upon the quality of life of their husbands. This study is a companion proposal to an ongoing, DOD-funded prospective study that is evaluating the outcomes of genetic testing for breast-ovarian cancer susceptibility on women from hereditary breast cancer families (C. Lerman, Principal Investigator, Georgetown University Medical Center). This second study extends the ongoing DOD-funded study to examine the impact of genetic testing upon the marital relationship and the psychosocial impact on the spouse. Specific aims of this study are: 1) to evaluate the short- and long-term impact of BRCA1/2 testing on psychological distress (both general and cancer-specific) of husbands of participants in genetic testing programs; 2) to evaluate the short- and long-term impact of BRCA1/2 testing on the marital relationships of participants and husbands, and examine whether marital satisfaction is an early predictor of psychological morbidity among participants in genetic testing programs and their spouses; 3) to examine the association between spouse responses during the testing process and carriers' distress post-notification.

### Background and Study Rationale

Recent molecular studies have led to the identification of a major breast-ovarian cancer susceptibility gene, called BRCA1 (Miki et al., 1994). About 5-10% of all breast cancer cases are attributed to BRCA1 mutations. Healthy women who have inherited BRCA1 mutations have 80-90% lifetime risk of breast cancer and 40-65% risks of ovarian cancer (Easton et al., 1993). Among women who are affected with breast cancer, those with BRCA1 mutations are believed to have a 38% 10-year risk and a 65% cumulative risk of second primary breast cancers (Easton et al., 1995). A second susceptibility gene (BRCA2) is estimated to account for an additional 5% of breast cancer cases (Wooster et al., 1995) and is also associated with an elevated risk of ovarian cancer (Berman et al., 1996; Thorlacius et al., 1996). The prevalence of mutations in BRCA1 and BRCA2 is higher in certain subgroups of breast cancer patients, such as Jewish women, younger women and those with family histories of cancer.

Evaluations of the psychosocial impact of BRCA1/2 testing indicate that, although BRCA1/2 testing may not generate significant psychological morbidity (Lerman et al., 1996), a subset of gene mutation carriers may be vulnerable to test-related psychological distress (Croyle et al., 1997). As yet, nothing is known about the impact of BRCA1/2 testing on husbands of testing participants. Spouses may be vulnerable to psychological distress for several reasons. First, if the couple has children, the husband may worry about the threat of a possible altered breast cancer gene passed on to the children. If the couple is still planning on having children, the husband may have concerns about future childbearing. Indeed, our prior research suggests that concerns about implications for altered breast cancer gene passed on to children are important to high-risk women (Lerman et al., 1995) and that testing may impact on reproductive plans (Lerman et al., 1994).

Second, a husband may worry about the later development of cancer in his wife. The expectation of caregiving to an ill spouse, as well as worry about possible loss of the wife to cancer may each cause distress. Third, if the wife is distressed by the risk notification, her distress is likely to be conveyed to her spouse and is likely to lead to the husband becoming distressed. Indeed, studies of cancer patients and their spouses have suggested that spousal distress levels are highly correlated (Northouse, 1988).

In addition to impacting husbands' distress, genetic testing may place strain on the marital relationship. Our pilot data indicate that most couples discuss decisions (e.g., whether or not to undergo testing). Difficulty in communication during these discussions can result in less satisfaction with the marital relationship for both partners. Our prior research among cancer patients suggests that, if the patient feels constrained in his or her ability to talk with the spouse about emotional concerns, this leads to decreased marital satisfaction and

psychological distress for patients (Manne et al., 1997; Manne et al., 1997). A second source of marital strain may be the support-related interactions between women and their spouses. Individuals typically seek support from their spouses when they are distressed and unsupportive responses by spouses are a main determinant of marital dissatisfaction (Gottman et al., 1989). If genetic testing participants do not receive the expected spousal support, marital strain is likely. In addition, couples who begin the testing process with marital problems may be particularly vulnerable to increased marital strain when they receive notification of a genetic mutation. Most of the psychological literature dealing with families at high risk for breast-ovarian cancer focuses on either the affected individual or the person genetically at risk (Lerman et al., 1996; Croyle et al., 1997). Almost no attention has been paid to the spouse of the individual at risk or the spouse's response to notification of carrier status. There are a limited number of studies which examine the psychological impact on spouses of predictive testing programs for Huntington's disease (HD) which indicate that partners of HD carriers experience marital distress (Codori et al., 1994; Quaid et al., 1995; Tibben et al., 1993). Tibben et al. (1997) found that partners had similar patterns of psychological distress over a 6-month follow up compared to tested individuals. Both carriers and their partners evidenced distress returning to pretest levels over the 3 year follow up. However, among noncarriers, different patterns were found for carriers and their partners. Whereas noncarriers' partners had significantly lower levels of intrusive thoughts and avoidance at the 3 year follow up, the levels of intrusive and avoidant thoughts were at pre-test levels for noncarriers themselves. Partners of carriers who had children were more hopeless and distressed than partners without children, illustrating the important role of worries about children. Given that the illness course of HD is difficult and disease prevention is not possible, it is not known whether similar psychological responses occur among partners of BRCA carriers.

**Significance of the Study**

As yet, the impact of genetic testing for breast cancer on spouses or on the marital relationship has not been studied. This study will be the first to examine psychological outcomes for spouses. In addition, prior work has not examined the role of the spouse's support/lack of support on the participant's psychological responses to the genetic testing experiences. Our studies of breast cancer patients indicate that women who experience many breast cancer worries and feel constrained in their ability to talk to their spouse are more likely to have emotional distress during their treatment. The proposed study will examine this possibility among high risk women who receive positive results for mutations in BRCA1/2.

This research would make several important contributions to the empirical literature as well as have implications for genetic testing programs. First, although it is well-known that carrier notification has implications for the whole family, the majority of studies to date have examined the impact at an individual level, neglecting effects on family members. This study would quantify the impact on the spouse, and identify those spouses who are vulnerable to a poor psychological outcome after testing. Distressed spouses may benefit from adjunctive psychological support during the testing process. Second, the results may have implications for genetic testing programs. If disclosure of results causes marital strain for some participants, then participants might benefit from the inclusion of spouses in disclosure sessions or training in more effective methods of facilitating disclosure of results. Identification of couples "at risk" for marital and psychological strain during this process can be facilitated. Third, those participants with low levels of spousal support might be targeted for adjunctive therapies that bolster social support. This information would help providers anticipate and more effectively deal with problems that may arise in clinical genetics programs.

In addition, this research would have important implications for the way in which genetic counseling and testing programs are currently being conducted. If disclosure of results causes strain for some participants, then participants might benefit from the inclusion of spouses in disclosure sessions or training in more effective methods of facilitating disclosure of results to family members. If mutation carriers who have more distressed marriages at the onset of the testing process or carriers who perceive more constraints in their ability to talk with their husbands about concerns related to breast cancer are particularly vulnerable to poor psychological outcomes, these participants can be identified early and these women can be offered adjunctive therapies that bolster social support from other sources, or offered marital counseling. The information provided by this study

would assist genetic testing providers to anticipate and more effectively deal with problems that may arise in clinical genetics programs.

**Preliminary Studies**

*Lerman et al. (1996)* examined 279 members of breast-ovarian families and found that noncarriers of BRCA1 mutations showed significant decreases in depression compared to carriers and decliners of testing one month post-notification (1996). There were no significant changes in carriers or decliners. These results indicate that, at least in the short term, the majority of high risk individuals do not evidence significant psychological distress. However, there was variability in the distress measure, indicating that education or other psychological factors might contribute to differences in psychological impact of testing. This study also did not identify individual differences in responses to testing, including the impact on family relationships.

*Manne* conducted a pilot study of 20 high risk women participating in the genetic testing program for breast-ovarian cancer at Memorial Sloan-Kettering Cancer Center. Women were administered questionnaires pre-genetic counseling, one month post-genetic counseling and one month post-test notification (1/14 tested positive). Pre-counseling: 90% of women discussed the decision to seek testing with their spouses and sought spouse advice. On average, spousal advice was rated as having "somewhat" of a role in the testing decision. Most women planned to disclose results to their husbands (90%). On average, participants anticipated a little difficulty in sharing results and felt husbands would be "somewhat" supportive during the discussion of test results. Post-counseling results indicated that most participants discussed the results of the counseling session with their husbands. On average, they rated their spouses as "somewhat" supportive and felt the process had placed "a little" strain on the marital relationship. A subsample of 20% of participants reported that their spouses had avoided discussing the issue and reported that the process placed some strain on the relationship. One month post-notification: only 1/14 participants were carriers (too small for statistical comparisons). All but one of the women had disclosed results to their spouses. Whereas marital strain imposed by testing was relatively low in the majority, 30% stated their spouses "somewhat avoided" discussing the testing and half rated their spouses as "somewhat supportive" (3 on a 5 point Likert scale).

**BODY**

**Technical Objectives**

We are conducting a prospective study to evaluate the impact of genetic testing for breast-ovarian cancer susceptibility on the marital relationships of women at risk as well as the impact upon the quality of life of their husbands. This study is a companion proposal to an ongoing, DOD-funded prospective study that is evaluating the outcomes of genetic testing for breast-ovarian cancer susceptibility on women from hereditary breast cancer families (C. Lerman, Principal Investigator, Georgetown University Medical Center). The proposed study extends the ongoing DOD-funded study to examine the impact of genetic testing upon the patient's perceptions of the marital relationship and the psychosocial impact on the spouse.

*Aim 1: To evaluate the short- and long-term impact of BRCA1/2 testing on psychological distress (both general and cancer-specific) of husbands of participants in genetic testing programs.* At 1- and 6-months post-notification, husbands of women who have a confirmed BRCA1/2 mutation will have increased psychological distress (general and cancer-specific) compared with husbands of non-carriers (NC) and test decliners (TD). At 12 months, there will be no differences between the three groups.

*Aim 2: To evaluate the short- and long-term impact of BRCA1/2 testing on the marital relationships of participants and husbands, and examine whether marital satisfaction is an early predictor of psychological morbidity among participants in genetic testing programs and their spouses.* It is hypothesized that, at 1- and 6-months post-notification, husbands of women who have a confirmed BRCA1/2 mutation (Mc) will have decreased marital satisfaction compared with husbands of non-carriers (Nc) and test decliners (Td). At 12

months; there will be no differences between the three groups. It is hypothesized that, for participants with high levels of marital satisfaction at baseline, marital satisfaction will not change significantly from pre- to post-notification (Mc, Nc, Td). For participants with low levels of marital satisfaction at baseline, carriers' marital satisfaction will decrease over the one year follow-up whereas noncarriers' and decliners' marital satisfaction will not change over the 1 year follow-up. Similar predictions are made for husbands.

*Aim 3: To examine the association between spouse responses during the testing process and carriers' distress post-notification.* Carrier women who evidence high levels of cancer-related worries and experience more constraints in their ability to talk to their spouse about the testing experience will evidence more psychological distress and lower marital satisfaction at 1-, 6- and 12-months post-notification.

**Methods**

*Overview of Study Design*

Parent DOD study (C. Lerman, Principal Investigator). The parent study is ongoing at Georgetown University Medical Center. All women recruited for the parent study are recruited from this study site. In this prospective longitudinal study, eligible women are invited to participate in a baseline telephone interview. Subsequently, they are invited to participate in a Pre-Test education session and are offered a test for the BRCA1 mutation known to be segregating in their family. The results of this test are presented at an individual genetic counseling session. All women receive follow-up phone interviews at 1-, 6-, and 12-months post-disclosure. Persons who agree to participate in the study but decline Pre-test education and/or mutation status determination receive the same telephone interviews. Analyses compare mutation carriers, noncarriers and participants who decline testing.

*Participants*

**Eligibility criteria**

Familial risk subjects. Persons eligible for this study are married individuals, ages 18 and older, who are members of HBOC families in which as disease conferring mutation has been identified, and their spouses. We estimate that about 30% of the sample will be affected (statistical analyses will control for status-affected vs. at-risk). Subjects are ineligible for this study if either they have a psychiatric or cognitive disorder which precludes informed consent.

Based on current figures for accrual for the ongoing study, 5 women per week will be eligible for participation. Study accrual will span two and one half years. Seventy percent of the pool of 650 women will be married (N= 455). Of these 455, current figures from the ongoing study suggest that 30% (137) will decline mutation status testing. If 318 women elect to receive test results, about 145 (32%) should be mutation carriers and 172 (38%) noncarriers (there are more non-carriers since some subjects will be at 25% risk). Ten percent of participants drop out of the study by the one year follow-up, with a final sample size of 410: N, carrier group=130, N, noncarrier group=152, N, decline testing=130. Women will be eligible for the study if their spouse declines participation (this is relevant to sample size for Aim 3). From the PI's ongoing study of couples with cancer, it is anticipated that 10% of spouses will decline participation. Thus the final sample size of husbands is 370 (of which 110 are carrier couples). Given our current sample, we expect that 65% of subjects will be white, 25% African American, 5% Hispanic, and 5% Asian/Pacific Islander or Native American.

*Procedures*

All study procedures for familial risk subjects are conducted at Georgetown University Medical Center. After informed consent is received from the female participant and consent is given to contact the participant's husband, the husband's name, address and telephone number will be provided (by telephone) to the Research

Study Assistant at Fox Chase Cancer Center by the Research Study Assistant at Georgetown. All study procedure activities for husbands will be conducted at Fox Chase Cancer Center.

Identification of subjects. Procedures for identifying eligible HBOC families are described in detail in the funded DOD parent grant. We will provide an abbreviated description of study procedures and focus more on spousal recruitment procedures.

Recruitment of participants. Procedures are being used successfully in the ongoing study that forms the basis for this proposal. Informed consent procedures are consistent with the guidelines of the NIH/National Center for Human Genome Research (NCHGR) cancer Studies Consortium, of which Dr. Lerman is a member.

Recruitment of spouses. The introductory letter will include a description of the desire for spouse participation and a rationale for the inclusion of spouses in the study. When women are contacted for oral consent for the baseline telephone interview, permission to contact the spouses will be obtained. It will be stressed that permission to contact spouses is not a requirement for participation in the individual portion of the study. A letter will be sent to spouses immediately after permission is given to contact them. Written informed consent for the telephone interviews with the spouses will be obtained.

Assessment Procedures for Familial Risk Participants

A chart outlining measures to be administered at each study timepoint is shown below (see figure below).

Baseline Telephone Interview: Telephone interviews are used successfully in ongoing data collection. A subset of the measures already being administered in the parent DOD-funded study will be used for data analyses in the current study. These measures are: cancer-specific distress (RIES), general distress (Hopkins Symptom Checklist-25), and general family relationship quality (Family Relationship Inventory). The following additional measures will be administered (see measures for complete description): husband's support and encouragement for genetic testing, whether or not decision to seek testing was discussed with the husband, plans to disclose test results to the spouse, degree of strain/positive impact of testing process on marital relationship, degree of desire to talk about genetic testing, actual talking about genetic testing, perceived negative behaviors engaged in by spouse, protective buffering, closeness of the marital relationship, and marital satisfaction. Women who decline testing will be asked to fill out a subset of the measures that are relevant to them (distress, marital satisfaction, family relationship quality).

At the end of the interview, participants are invited to attend a Pre-Test Education session. Those who decline are asked if we may contact them for follow-up interviews, and contact their spouses for potential recruitment for the spouse part of the study.

In the ongoing study, there is 80% compliance with interviews, even among decliners.

In addition to the information already being collected (cancer-specific and general distress), the following will be administered: plans to disclose test results to the spouse, strain of testing process on marital relationship, perceived constraints in talking to the spouse, and marital satisfaction.

A Pre-Test Standard Education Session will be conducted within the next four weeks among consenting subjects. Written consent is obtained from all subjects prior to the education session. A genetic counselor conducts all sessions, under the supervision of a medical oncologist and Dr. Lerman.

Determination of Carrier Status, Genetic Counseling/Disclosure of Genetic Test Results, Cancer Prevention/Surveillance Recommendations. Mutation status tests and counseling are offered to all high risk females. Informed consent, procedures and topics covered in the Disclosure session are described in the Appendix. At the patient's discretion, a spouse or companion may be present at this meeting (controlled for in statistical analysis).

Follow-up Genetic Counseling is conducted by telephone about two weeks after disclosure of mutation status (only for those subjects who received test results).

Follow-up Telephone Interviews are conducted at 1-, 6- and 12-months after the individual genetic counseling session for subjects who received results of mutation testing. Subjects who declined to be tested will be contacted for follow-up at these time points after the Pre-Test Education date of their index family member (proband). Telephone interviews are conducted (by blinded interviewers) to reassess measures included in the ongoing study.

Data collection procedures: Spouses. After spouses give written consent for the telephone interview, they will be administered surveys by phone at the same times as the wives are administered surveys: baseline, 1-, 6- and 12-months after the individual genetic counseling session for spouses of subjects who received the test results.

Telephone interviews will be supervised by Dr. Audrain (women) and Dr. Manne (spouses). Telephone interviews are used successfully in ongoing data collection. At the end of the interview, women are invited to attend a Pre-Test Education session. Those who decline are asked if we may contact them for follow-up interviews. In the ongoing study, there is 80% compliance with interviews, even among decliners.

Measures given to both partners, all time points: 1) Cancer-Specific Distress: The Impact of Events Scale (IES) is a 21-item scale that has intrusion and avoidance subscales; 2) Hopkins Symptom Checklist-25: a 25-item Likert scale indicating severity of anxiety and depression; 3) Dyadic Adjustment Scale: widely-used 32-item scale assessing marital satisfaction (Kagan et al., 1991). Subscales include cohesion, satisfaction, affection and consensus; 4) Marital Strain: 2 items assessing marital strain during testing process. Additional measures for women: 1) Baseline: a) whether decision to seek genetic testing was discussed with spouse; b) whether subjects plan to disclose test results to spouse; c) constraints in talking with husband about breast cancer and testing (5 items; adapted from Lepore's (Lepore et al., 1996) scale); 2) Post-notification: a) whether or not test results were disclosed; b) spouse supportive/unsupportive responses during discussion; c) if no disclosure was made, whether or not disclosure is planned; d) constraints. Additional measures for husbands: 1) Baseline: a) whether decision to test was discussed; 2) Post-notification: a) whether test results were disclosed; 3) All time points: Cancer-specific distress/concerns (in addition to IES): Worries about testing effects on: a) children; b) childbearing decisions; c) worry about possible cancer diagnosis; d) worry about caregiving responsibilities should the wife be diagnosed.

Data Analysis: **Hypothesis 1:** The two dependent measures (husband IES, HSCL) will be examined individually (i.e., univariate analyses) and together (multivariate analyses) using multifactor fixed effect ANOVA and ANCOVA with blocking on family (women are from hereditary families). The 1-, 6-, and 12-month post-notification responses will first be analyzed separately with baseline response used as a covariate. The two dependent variables will be analyzed together using repeated measures ANOVA, with the between groups factor as test group (Mc, Nc, Td). The independent variables include: (1) whether the woman is affected and (2) whether the husband was present during counseling and disclosure of test results. We will also explore the influence of other relevant sociodemographic variables and interactions (e.g. husband education, ethnicity). These tests of interaction effects will identify variables which modify the impact of testing among husbands of carriers, noncarriers, and test decliners. **Hypothesis 2:** The analysis of DAS scores of husbands and wives will

be analyzed separately using the same ANOVA and ANCOVA approaches outlined above for husband distress. For the second question, we will examine the influence of marital satisfaction at baseline on post-notification marital satisfaction of women and husbands. High and low marital satisfaction will be determined by a median split on the baseline DAS variable. A repeated measures MANOVA will be conducted separately for the two indicators of marital satisfaction (general marital satisfaction and marital strain). Baseline general marital satisfaction will be entered into the analysis. We will examine differences in marital satisfaction over time between the three groups (Mc, Nc, Td) using ANOVA approaches outlined above. It is predicted that carriers and husbands with low marital satisfaction at baseline will evidence more marital dissatisfaction post-notification than carriers with high marital satisfaction or noncarriers and test decliners with low or high marital satisfaction. **Hypothesis 3:** This analysis will be conducted on women who are carriers. We will use separate regression analyses with women's psychological distress and marital satisfaction at 1-, 6- and 12-months post-notification as dependent variables. We enter first into the equation sociodemographic variables which predict distress and marital satisfaction. Next, we will enter: 1) baseline distress, 2) intrusive thoughts about cancer, 3) constraints in talking with the husband, 4) the interaction term between intrusive thoughts and constraints (centered). It is anticipated that the interaction term will be significant. **Power Analysis:** The design of the study is essentially one of clustered sampling, since study subjects are identified on the basis of family membership. Outcome measures will be considered at the four time points. Between participant factors will include test result (carrier, noncarrier, decliners). An interaction effect would reveal a different course of psychological responses over time. *This is not done yet.*

**Preliminary Results**

We will report baseline (pre testing) data from 116 spouses and 141 genetic testing participants. We will also report one-month post-disclosure follow-up data on the 56 participants and spouses who received mutation positive and negative results. We are not presenting test decliner or ambiguous test result outcomes at this time.

Sample Characteristics

The mean age of the spouses was 53 years. 94% were Caucasian. Spouses had been married 1 to 55 years (median time=22 years). The mean age of genetic testing participants was 50 years. 97% were caucasian.

Baseline Associations between partners' marital dynamics and psychological distress

| | HSCL total | | State Anxiety | |
|---|---|---|---|---|
| | **Participant** | **Partner** | **Participant** | **Partner** |
| **Protective Buffering** | | | | |
| Participant | .30** | | .19 | |
| Partner | | .38*** | | .34*** |
| **Negative Partner Behaviors** | | | | |
| Participant | .30** | | .15 | |
| Partner | | .49*** | | .34*** |
| **Partner Encouragement for Testing** | -.13 | | -.22* | |
| **Partner Negative Opinions about testing** | .06 | | .21* | |
| **Comfort sharing concerns with partner** | | | | |
| Participant | - .24* | | -.10 | |
| Partner | | -.21* | | -.18 |
| **Partner's supportive responses to concerns raised** | | | | |
| Participant | -.16 | | -.18 | |
| Partner | | -.11 | | -.14 |

These findings suggest that unsupportive responses by spouses, and spousal lack of comfort sharing concerns with the genetic testing participant, are associated with more distress on the part of both participants and their spouses.

Baseline to 1-month post-disclosure: General Psychological Distress, Cancer-Specific Psychological Distress.

Means and standard errors for the main variables of interest are reported in the table below. The groups were broken down into affected carriers (had cancer, positive mutation), unaffected cancer (did not have cancer, positive mutation), and true negatives. Participant and partner scores are reported separately. **Lower** scores for cancer-specific IES, psychological distress, and state anxiety indicate better psychological profiles. **Higher** scores for marital adjustment indicates a greater satisfaction with the marital relationship.

| | **Participant** | | | **Spouse** | | |
|---|---|---|---|---|---|---|
| | **Affected Carrier** | **Unaffected Carrier** | **Non Carrier** | **Affected Carrier** | **Unaffected Carrier** | **Non-Carrier** |
| **HSCL total** | | | | | | |
| Baseline | 43.20 (13.96) | 37.20 (10.93) | 33.50 (4.45) | 37.67 (8.59) | 36.25 (9.62) | 33.80 (9.78) |
| 1 Month | 33.87 (7.57) | 36.30 (13.45) | 34.40 (6.93) | 35.77 (7.62) | 37.38 (10.24) | 34.80 (6.34) |
| **State Anxiety** | | | | | | |
| Baseline | | | | 12.11 (8.37) | 15.25 (12.09) | 9.00 (11.08) |
| 1 Month | | | | 14.33 (12.34) | 17.62 (12.27) | 12.00 (8.37) |
| **IES Total** | | | | | | |
| Baseline | **22.63 (20.67)** | **12.73 (15.23)** | **20.55 (16.18)** | 30.43 (13.50) | 24.00 (33.94) | 27.33 (37.29) |
| 1 month | **12.95 (17.22)** | **20.73 (21.35)** | **14.27 (13.35)** | 26.57 (14.25) | 15.50 (21.92) | 33.66 (35.01) |
| **Marital Satisfaction** | | | | | | |
| Baseline | 124.8 (7.7) | 102.8 (31.5) | 122.7 (10.7) | 116.6 (18.3) | 115.4 (21.9) | 128.2 (5.3) |
| 1 month | 118.9 (9.7) | 92.8 (46.7) | 120.8 (17.7) | 114.7 (24.2) | 115.9 (26.1) | 124.4 (9.6) |
| **Marital Strain** | | | | | | |
| Baseline | .42 (.90) | .57 (.98) | .13 (.35) | *.50 (.97)* | *.86 (.83)* | *.33 (.52)* |
| 1 Month | .33 (.89) | .71 (.95) | .00 (.00) | *.40 (.97)* | *1.50 (1.7)* | *.17 (.41)* |

Note. Bold indicates significant Group X Time interaction effect. Italics indicate significant trend (p= .08).

To date, our findings suggest that affected carriers have a significant increase in IES scores at the one-month follow-up, unaffected carriers and true negatives have a significant decrease in IES scores at the one-month follow-up. Partners evidence no significant changes in psychological distress. While general marital satisfaction evidences no changes for either participants or spouses, cancer-specific marital strain evidences a trend towards increasing among spouses of unaffected carrier participants, a finding that is parallel to the increased IES scores in this group of carrier participants.

Six and one –year follow-up data will be available for analysis at the end of this year when there are sufficient numbers of couples in each of the test-status groups.

## Statement of Work

*Task 1 -- Month 1*
*Refine measures and train interviewers, plan communication between two sites, Georgetown and Fox Chase.*

a. The measures have been finalized.

b. Questionnaires have been Xeroxed.
c. Resident Assistants have been trained to conduct the interviews.
d. The procedures for sharing information between Georgetown and Fox Chase have been developed and tested.

*Task 2 -- Months 2-29*
*Subject Recruitment and Data Collection as of June 1, 2000*

a. 294 eligible individuals have been approached at Georgetown University for interest in participating in the study. 197 (67%) of these women have given consent for the study. 185 spouses have been approached at FCCC for interest in the study. 140 (75%) gave informed consent.
b. 143 participants have completed baselines surveys, 98 have completed one-month, 53 have completed 6-month, and 30 have completed one year follow ups. 117 spouses have completed baselines, 73 have completed one month, 36 have completed 6 month, and 15 have completed one
c. Interviews have been supervised by Drs. Manne (FCCC) and Audrain (GUMC) on a weekly basis.

*Task 3 -- Months 1-3*
*Data screens set up; data entry begun at Fox Chase*

a. Data at GUMC are collected using Computer Assisted Telephone Interviewing (CATI) and screens have been established at that site for this purpose.
b. Data at FCCC are not collected using CATI. Data entry screens have been established.
c. Data entry has been ongoing for several months at Fox Chase Cancer Center.

*Task 4 -- Months 29-36*
*Completion of follow-up interviews*

a. Follow-up interviews will be completed for accrued patients and spouses.

*Task 5 -- Months 30-36*
*Data analyses*

a. Encrypted data is being transferred on an ongoing basis by email from GUMC to FCCC.
b. Data analyses has been conducted to test the impact of testing and declining upon partners' marital satisfaction, marital strain, and psychological distress of husbands.

**KEY RESEARCH ACCOMPLISHMENTS**

As we are still collecting data and the findings reported above should be considered preliminary, there are no key research accomplishments yet.

**REPORTABLE OUTCOMES**

The baseline data reported above were presented at the Society of Behavioral Medicine meeting in Nashville. The report is contained in the appendix.

## CONCLUSIONS

Our baseline data suggest that the degree to which couples talk about, and feel comfortable talking about, their feelings and concerns about genetic testing are associated with psychological distress for both participants in these programs and their spouses. Spouse support and encouragement for the genetic testing decision is also associated with less anxiety on the part of participants. Our one-month follow-up data indicate that cancer-related distress increases among carriers who did not have a history of cancer, while it decreased among non-carriers and true negatives. There were no differences in distress among spouses of participants in the testing-outcome groups. There was a trend for spouses of carrier participants who had no history of cancer to report more marital strain associated with testing in comparison with spouses of non-carriers and spouses of carrier participants with a history of cancer. However, these data await further analyses with larger sample sizes.

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APPENDICES

A. CONSENT FORM
B. POSTER PRESENTATION

IRB#98-802 Version 5.0, August 1999

INFORMED CONSENT FOR CLINICAL RESEARCH

SPOUSE INFORMED CONSENT

I am being asked to participate in a research study which will evaluate the impact of education and counseling about genetic testing for breast and/or ovarian cancer. I have been told that I have the option not to participate.

The nature of this study, the risks, inconveniences, discomforts, and other pertinent information about the study are explained below. I am urged to discuss any questions I have about this study with the staff members who explain it to me.

The title of this research study is: IMPACT OF BRCA1/2 TESTING ON MARITAL RELATIONSHIPS.

Purpose of the Research Study:

The study will examine the impact of genetic testing for an increased risk of breast and/or ovarian cancer on the marital relationships of individuals at risk, as well as the impact upon the quality of life of their spouses. Genetic testing for cancer risk can be stressful for both the person at risk and his/her spouse. The investigators are interested in understanding these issues.

Description of the Research Procedures:

I understand that this study involves research. If I consent to participate, I will be asked to complete phone interviews at four different points in time. The first interview will occur prior to my spouse's participation in an education session about the genetic testing. The three remaining interviews will be conducted at approximately 1-,6-, and 12-month intervals following the session.

Each interview will ask questions about marital satisfaction, psychological well-being, and concerns about the impact of the genetic testing. Each interview should take approximately 30-45 minutes.

My spouse will also be asked to complete similar inteviews. My responses to the interviews are completely confidential, as are my spouse's responses.

Other than time required for participation (a total of 2-3 hours over a 1 year period), this study will not involve changes in my daily activities.

As a way of thanking me for my participation, the investigators will provide me with a coupon redeemable for one movie rental at Blockbuster for each survey which I complete.

Risks

This study involves research that presents minimal risk. While there are no physical risks/side effects involved in my participation, there is the possibility of psychological distress. It is possible that

answering questions contained in the interview may be upsetting. Should I become upset, the principal investigator will be available to provide reassurance, and, if appropriate, a professional referral.

Although unlikely, if I am injured as a result of my participation in this research study, emergency care, hospitalization, and outpatient care will be made available by the hospital and billed to me. No money will be provided by the hospital as compensation for a research-related injury.

Benefits

No guarantee is being offered that I will benefit from this study; however, the investigators have reason to believe that the information I provide will be beneficial to future couples undergoing genetic testing. Although the investigators hope that this research study will be of benefit to me, or that it will help others, they cannot say that it will help me directly.

If I wish, I will be informed of the results of this study when it is completed.

Financial Cost

Participation in this study will not involve any additional financial costs.

Confidentiality

My responses to these interviews are confidential. Both interviews and computerized data from the interviews will be kept confidential. I understand that my answers to the interviews will not be shared with my spouse without my express permission, and my spouse's answers to the interviews will not be shared with me without his/her permission.

I understand that there is a possibility that authorized individuals from government agencies such as the Food and Drug Administration, Office of Protection from Research Risks, U.S. Army Medical Research and Material Command may review my records as part of their responsibility to protect human subjects in research.

My name or any other personally identifying information will not be used in reports.

Questions

If I have questions about the research, or in the event of a research-related injury, I may contact the Institutional Review Board which is concerned with protection of participants in research projects. I may reach the Board office by calling (215)-728-2518, 9:00 am to 5:00 pm, Monday to Friday, or by writing the Institutional Review Board, Fox Chase Cancer Center, 7701 Burholme Avenue, Philadelphia, PA 19111.

I am free to ask questions at any time about these procedures and to ask for additional information. If I have questions, I can reach Dr. Sharon Manne, the psychologist conducting the study, at (215)-728-2896.

Significant Findings

As the research progresses any significant new findings, beneficial or otherwise, will be told to me and explained as related to my case.

Right to Refuse or Withdraw

Participating in this study is voluntary. I may refuse to answer any specific question or interview items. I understand that I am free to withdraw my consent to participate in this study at any time. If I withdraw, there will not be penalty or loss of benefits.

IRB#98-802 Version 5.0, August 1999

INFORMED CONSENT FOR CLINICAL RESEARCH

SPOUSE CONSENT

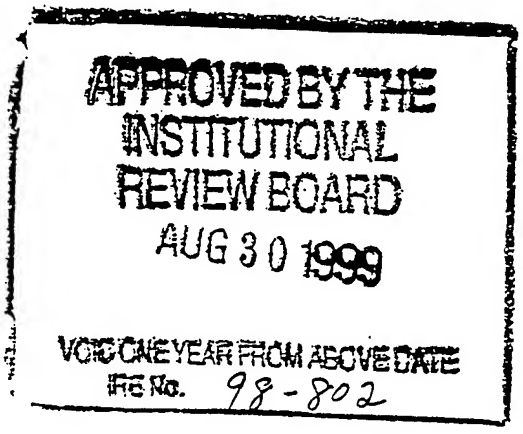
TITLE: IMPACT OF BRCA1/2 TESTING ON MARITAL RELATIONSHIPS

By signing below, I indicate that I have read this form, received acceptable answers to any questions, and willingly consent to participate. I will receive a copy of this form.

Date _____ Investigator's Signature _____

Date _____ Spouse's Signature _____

Name (Print) _____



# Marital Impact of BRCA 1 / 2 Testing

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Poster presented at the Annual Meeting of the Society of Behavioral Medicine, April 5 to 8, 2000, Nashville, Tennessee.

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## INTRODUCTION

Studies examining the psychosocial impact of BRCA 1 /2 testing indicate that, although BRCA 1/ 2 testing may not generate significant psychological morbidity, a subset of gene mutation carriers may be vulnerable to test-related psychological distress (Lerman et al., 1998). Although psychological impact of genetic testing on participants has been studied, very little attention has been paid to factors that may influence the psychological outcome of the genetic testing process. Recent studies have found higher levels of distress among mutation carriers with no history of cancer or cancer-related surgery (Croyle et al., 1997). However, other potential factors predicting response to mutation testing have not been identified. In particular, the role of spouse supportive and unsupportive reactions during the testing process have not been examined. In addition, little attention has been given to the impact of mutation testing on spouses.

The aims of the present study were threefold:

*Aim 1:* To determine the degree to which genetic testing participants and their partners discuss the decision to seek genetic testing and the degree to which partners are supportive;

*Aim 2:* To determine whether the genetic testing process places strain on the relationships of genetic testing participants and their partners;

*Aim 3:* To examine the association between partner support and communication about genetic testing and the level of psychological distress and test-related marital strain reported by genetic testing participants and their partners.

## METHODS

Members of Hereditary Breast Ovarian Cancer (HBOC) families were identified by Lombardi Cancer Center Assessment and Risk Program (CARE) through family history forms completed by patients, physician referral and self-referral.

After obtaining informed consent for the genetic testing study, participants were asked whether they wished to participate in a Marital Study. Participants who were married (or living with a significant other of either gender) were asked whether their significant other could be contacted regarding the Spouse study. After permission was obtained, significant others (partners) were contacted about the Spouse study.

There were four assessments in the longitudinal study: Prior to the pre-testing educational session; one month, six months and one year after disclosure of carrier status. Participants and partners completed questionnaires at the same time points.

The *Baseline* data formed the basis for the present study.

**SAMPLE**

197 participants provided informed consent. Of these, 129 (65%) completed baseline questionnaires.

176 partners were identified. Of these, 120 (68%) provided informed consent. To date, 104 partners have completed baseline assessments.

## SAMPLE CHARACTERISTICS

| | Participants (N = 129) | Partners (N=104) |
|---|---|---|
| Gender | | |
| Male | | 100% |
| Female | 100% | |
| Age | | |
| Mean | 50 years | 53 years |
| Range | 27-75 years | 29-87 years |
| Ethnicity | | |
| Caucasian | 98% | 94% |
| Education | | |
| High school graduate | | 10% |
| College graduate | | 14% |
| Graduate level degree | | 45% |
| Income | | |
| Median | | $60,000 |
| Number of years married | | 22 years |
| Affected Status | | |
| Cancer | 27% | |
| No cancer history | 73% | |
| Proband Status | | |
| Proband | 75% | |
| Relative | 24% | |

## BASELINE MEASURES

Test-specific marital process

Was the decision discussed with partner?

Does the partner think participant should undergo testing?

What was the partner's response to these discussions:
- Was partner supportive?
- Did partner avoid discussion?

Is the partner supportive/encouraging of the decision to pursue testing?

Sharing and comfort talking about concerns related to testing (2 items)

Protective Buffering
- Hiding test-related worries or concerns
- Keeping feelings about testing to oneself; Avoiding conflicts since testing

Unsupportive Behaviors (9 items) (Partner's behavior only)
- Complained about own problems when participant wanted to talk
- Changed the subject when participant wanted to talk

General Psychological Distress

Hopkins Symptom Checklist (Anxiety and Depression)
State Anxiety Inventory

Cancer Specific Psychological Distress

Impact of Events Scale
Breast Cancer Concerns (partner only)

General and Cancer- Specific Marital Outcomes

Dyadic Adjustment Scale
Relationship Strain Associated with Testing

## DESCRIPTIVE STATISTICS

| | Participant | Partner |
|---|---|---|
| Marital Process | | |
| Support for testing | 10.61 (2.02) | ---- |
| Sharing Concerns | 8.12 (3.26) | 6.41 (2.11) |
| Unsupportive Behavior | 3.72 (6.57) | 2.28 (3.25) |
| Protective Buffering | 2.68 (4.25) | 3.30 (3.27) |
| Distress | | |
| HSCL Anxiety | 9.40 (2.82) | 8.27 (3.13) |
| HSCL Depression | 16.25 (5.36) | 15.24 (4.33) |
| State Anxiety | 15.13 (11.67) | 10.84 (10.50) |
| IES Intrusions | 8.98 (7.50) | 6.66 (6.94) |
| IES Avoidance | 8.50 (7.94) | 8.34 (9.18) |
| Concerns about cancer | ---- | 8.92 (3.13) |
| Marital Outcomes | | |
| Marital Satisfaction | 116.93 (15.9) | 116.98 (15.93) |
| Test-related Marital Strain | 7.0 (1.89) | 6.23 (2.34) |

## DISCUSSION ABOUT DECISION TO PURSUE GENETIC TESTING

| | | Participant | Partner |
|---|---|---|---|
| Have you and your partner discussed the decision to seek genetic testing? | | | |
| | Yes | 98.4 | 91.3 |
| | No | 1.6 (N=1) | 8.7 (N=2) |
| Did your partner understand your concerns about testing? | | | |
| | Not at all | 5.7 | 6.5 |
| | Somewhat | 32.7 | 40.2 |
| | Very much | 61.5 | 29.3 |
| Did your partner avoid discussing these issues with you? | | | |
| | Not at all | 87.2 | 92.3 |
| | Somewhat | 11.9 | 5.5 |
| | Very much | 0.9 | 2.2 |
| What is the level of your partner's support for testing? | | | |
| | None | 1.6 | |
| | Very little | 4.8 | |
| | Some | 20.2 | |
| | A lot of support | 72.6 | |
| What is the level of your partner's encouragement for testing? | | | |
| | None | 3.3 | |
| | Very little | 4.9 | |
| | Some | 24.4 | |
| | A lot of support | 66.7 | |

# CORRELATIONS BETWEEN MARITAL COMMUNICATION, PSYCHOLOGICAL DISTRESS, AND MARITAL SATISFACTION: PARTICIPANTS

| | Psychological Distress | | | | | Marital Satisfaction | |
|---|---|---|---|---|---|---|---|
| | Anxiety | Depression | State Anxiety | Intrusions | Avoidance | Test-Related Relationship Strain | General Marital Satisfaction |
| Age | -.16 | -.17 | -.22 | _ | -.18 | -.28** | _ |
| Cancer Status | _ | -.12 | -.30* | _ | _ | -.17 | .17 |
| Support of Testing | _ | _ | _ | -.21 | -.18* | -.18* | .32** |
| Unsupportive Behaviors | .48*** | .51*** | .12 | .17 | .25* | .39** | .25 |
| Sharing Concerns with Partner | -.17 | _ | .12 | .11 | .04 | .32* | _ |
| Protective Buffering | .56*** | .59*** | .31* | _ | .22 | .34** | -.44*** |
| Relationship Strain | .31* | .24* | .12 | _ | .16 | _ | -.25* |

* $p < .05$
** $p < .01$
*** $p < .001$

Note: Cancer status: 1 = No cancer, 2 = Cancer. Dashes note correlations $\leq .10$.
Higher scores denote more anxiety, depression, concerns, more strain, and higher marital satisfaction

# CORRELATIONS BETWEEN MARITAL COMMUNICATION, PSYCHOLOGICAL DISTRESS AND MARITAL SATISFACTION: PARTNERS

| | Psychological Distress | | | | | | Marital Satisfaction | |
|---|---|---|---|---|---|---|---|---|
| | Anxiety | Depression | State Anxiety | Cancer Concerns | Intrusion | Avoidance | Test-Related Relationship Strain | Marital Satisfaction |
| Age | -.25 | -.21 | -.13 | _ | -.12 | _ | _ | _ |
| Discuss Testing | -.11 | -.18 | _ | .15 | -.11 | _ | _ | .23* |
| Participant Understood Concerns | _ | _ | -.13 | -.21 | .23 | _ | _ | .24* |
| Unsupportive Behaviors | .33* | .38* | .46*** | -.38** | _ | .30* | .38*** | -.38*** |
| Sharing with Partner | _ | -.15 | -.16 | _ | _ | -.12 | -.12 | .16 |
| Protective Buffering | .19 | .45*** | .38*** | -.35** | .28*** | .34*** | .59*** | -.35*** |
| Relationship Strain | .20* | .23* | .19 | .24* | .25* | .28** | _ | -.19 |

* $p < .05$
** $p < .01$
*** $p < .001$

Note: Dashes note correlations ≤ .10. Higher scores denote more anxiety, depression, concerns, more strain, and higher marital satisfaction.

## HIERARCHICAL REGRESSION PREDICTING BASELINE ANXIETY

| Step and Variable | R square change | Final Beta |
|---|---|---|
| Dependent Variable: Participant HSCL Anxiety | | |
| Step 1 | .079 | |
| Participant Age | | -.225 |
| Cancer history | | -.036 |
| Step 2 | .078* | |
| Intrusive thoughts | | .218 |
| Step 3 | .220* | |
| Protective Buffering | | .347* |
| Partner's Unsupportive Behavior | | .182 |
| Partner's Support for testing | | .083 |
| Dependent Variable: Partner HSCL Anxiety | | |
| Step 1 | .063 | |
| Partner Age | | -.179 |
| Participant Cancer history | | .027 |
| Step 2 | .293*** | |
| Intrusive thoughts | | .563*** |
| Step 3 | .055 | |
| Protective Buffering | | -.089 |
| Unsupportive Behavior (self) | | .270* |
| Participant understood test-related concerns | | .024 |

**HIERARCHICAL REGRESSION PREDICTING TEST-RELATED RELATIONSHIP STRAIN**

| Step and Variable | R square change | Final Beta |
|---|---|---|
| Dependent Variable: Participant Marital Strain | | |
| Step 1 | .057 | |
| Participant Age | | -.117 |
| Cancer history | | -.061 |
| Step 2 | .004 | |
| Intrusive thoughts | | -.043 |
| Step 3 | .339*** | |
| Protective Buffering | | .315** |
| Partner Unsupportive Behavior | | .411** |
| Partner support for testing | | -.027 |
| Dependent Variable: Partner Marital Strain | | |
| Step 1 | .051 | |
| Partner Age | | -.088 |
| Participant Cancer history | | -.082 |
| Step 2 | .064 | |
| Intrusive thoughts | | .114 |
| Step 3 | .328** | |
| Protective Buffering | | .497*** |
| Unsupportive Behavior (self) | | .183 |

## SUMMARY OF RESULTS

*Aim 1a:* *To what degree do genetic testing participants and their partners discuss the decision to seek genetic testing with their partners?*

- Almost all individuals undergoing genetic testing discuss the decision to pursue testing with their partner.

*Aim 1b:* *How supportive are partners?*

- The majority of partners are extremely supportive of the decision to seek mutation testing. However, approximately 15-30% of participants report that their partners exhibit "no support", "very little" or "some" support.

*Aim 2:* *Does the genetic testing process place strain on the relationships of participants and their partners?*

- At Baseline, approximately 12% of participants and 23% of partners report some level of strain (prior to testing).

Aim 3: *What is the association between partner support and communication about genetic testing, and the psychological distress reported by genetic testing participants and their partners?*

- For participants, the most consistent associations between partner support and communication, psychological distress and marital strain were found for Protective Buffering, which was associated with Anxiety, Depression, and Marital Strain. Partner unsupportive responses to the testing process were also associated with participant's rating of test-related marital strain.

- For partners, the same pattern of results was found.

## CONCLUSIONS

- Participants in mutation testing programs discuss the decision to pursue testing with their partners.

- Marital communication, in particular, attempts on the part of both participants and partners to hide worries and concerns about the testing process, is associated with higher levels of test-related marital strain as well as baseline levels of psychological distress for both participant and partner.

- Whether the associations between marital communication, marital strain, and psychological distress persist after mutation status disclosure will be the focus of follow-up analyses.